



Structure Workgroup Meeting #3 – Summary

Tuesday, May 26, 2020

Thank you to everyone who joined and participated in our May workgroup meeting – the final one! As a reminder, this workgroup is focused on developing the structure that our proposed privacy framework for unregulated health data will take. On our April call, we discussed developing a private self-regulatory model with government support, and I held a number of calls with individual workgroup members following the meeting to think through the incentives to adopt such a model. At our May meeting, we discussed these various incentives and talked through a strawman proposal for what the model itself would look like.

Meeting Attendees

- Laura Hoffman (American Medical Association)
- Mark Segal (Digital Health Policy Solutions)
- Jeri Koester (Marshfield Clinic)
- Deven McGraw (Citizen)
- Jessica Rich (former FTC)
- Mary Engle (BBB)
- Po Yi (Manatt)
- Lee Tien (Electronic Frontier Foundation)
- George Mathew (DXC Technology)
- Robert Tennant (MGMA)
- Alejandro Roark (HTTP)
- Brooke Rockwern (ACP)
- Julie Barnes (Maverick Health Policy)
- Erin Mackay (NPWF)
- Andy Crawford (CDT)

Discussion

Summary of Meeting #1

- We began the meeting with a summary of the April meeting, during which the group walked through various self-regulatory models that might work in the healthcare context. Both the April meeting and a series of post-meeting discussions with individual workgroup members involved getting clarity on the incentives for various companies to join such a self-regulatory body, which most group members agreed should take the form of a private group with government support.



Industry Self-Regulatory Model with Government Support

- Potential incentives to join such a model could include:
 - Competitive and/or reputational advantage to voluntarily complying with a robust set of privacy practices and principles
 - Intermediate dispute-resolution mechanism to issues short of government enforcement
 - Reduced fear of government penalties or enforcement; likelihood that government penalties would be reduced given membership
 - Assurances or assistance with complying with federal and certain state privacy laws
 - Potential for FTC “blessing”

- The group discussed how the “carrots” and “sticks” need to be balanced in order for any model to work. Plus, positive reinforcement of privacy-protective and consumer-focused behavior needs emphasis in addition to potential enforcement and/or penalty mechanisms.

- With respect to the strawman proposal circulated in advance of the meeting (as drafted by Mary Engle and some BBB colleagues), there were a number of suggestions for clarification, additions and a couple of deletions.
 - These included whether or not non-participants in the body should be publicly called out; the precise steps a company would need to take in order to be certified as a member and what specifically that certification would look like (e.g. product- or company-level?); accountability mechanisms; the utilization of a public website; the process for complaint gathering; to what extent corrective action plans should address systemic issues; how to emphasize transparency in an effort to garner and maintain trust; the need to flesh out details of the funding mechanism; the importance of not overly aligning the group with a particular administration in order that the body endure beyond any one administration; and the need to specifically target and appeal to distinct audiences.
 - It was agreed that we need to start slow, even as we dream big; need to make this as simple as possible, at least at first.
 - Individual workgroup members are encouraged to send in redlines, comments and suggestions to the proposal by **Friday, June 12.**

Next Steps

- A number of workgroup members raised the question of whether we should build off an existing standards-setting or certification body, rather than starting from scratch. There



are a number of models to which we will look in the coming weeks, if only for “lessons learned.”

- Again, please send comments to the Strawman Proposal to Alice Leiter at alice@ehidc.org by next Friday.
- The full Steering Committee will meet again on **July 21**. We had, of course, planned to have this meeting in person, but understandably this meeting will now occur via web-conference. Details, the meeting agenda and pre-reads will be forthcoming.